



Number 15
December 2008

Fact Sheet

Obtaining Personal Health Information About a Deceased Relative

There may be circumstances in which a person may wish to obtain the personal health information of a deceased relative. For example, a person may wish to obtain the personal health information of a parent who has resided in a long-term care facility or who has been treated at a hospital emergency department, a sibling who has been estranged for some time or, tragically, a son or daughter who has died suddenly in an accident. There may be many reasons why obtaining such information is important to the surviving relative. For example, it may assist him or her in administering the deceased relative's estate, coping with the grieving process, or making knowledgeable decisions about his or her own health care or that of another relative.

Ontario's *Personal Health Information Protection Act, 2004 (PHIPA)* sets out rules for the collection, use and disclosure of personal health information by health information custodians. Since these rules continue to apply for a period of time after an individual has died, there may be limits to the amount of personal health information a person is able to obtain about a deceased relative.

This Fact Sheet provides answers to some common questions that are important in determining whether a person has the right under *PHIPA* to obtain personal health

information about a deceased relative from a health information custodian. It also provides some information about whether a person has the right to obtain medical information about a deceased relative held by a government institution covered by the *Freedom of Information and Protection of Privacy Act (FIPPA)* or the *Municipal Freedom of Information and Protection of Privacy Act (MFIPPA)* that is not also a health information custodian.

What is Personal Health Information?

In accordance with section 4 of *PHIPA*, "personal health information" means identifying information about an individual in oral or recorded form, if the information,

- (a) relates to the physical or mental health of the individual, including information that consists of the health history of the individual's family,
- (b) relates to the providing of health care to the individual, including the identification of a person as a provider of health care to the individual,
- (c) is a plan of service within the meaning of the *Long-Term Care Act, 1994* for the individual,



- (d) relates to payments or eligibility for health care, or eligibility for coverage for health care, in respect of the individual,
- (e) relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance,
- (f) is the individual's health number, or
- (g) identifies an individual's substitute decision-maker.

Personal health information also includes identifying information about an individual that is not personal health information, but that is included in a record containing personal health information.

How long is personal health information protected under *PHIPA*?

PHIPA continues to protect an individual's personal health information for a period of time after death. Specifically, *PHIPA* ceases to apply to an individual's personal health information 120 years after a record containing the information was created or 50 years after the death of the individual, whichever comes first.

What is a health information custodian?

As defined at section 3 of *PHIPA*, health information custodians include health care practitioners (defined at section 2), hospitals, psychiatric facilities, pharmacies, laboratories, nursing homes and long-term care facilities, homes for the aged and homes for special care, community care access corporations, ambulance services, boards of health, the Minister of Health and Long-Term Care and the Canadian Blood Services.

Does the estate trustee have a right to obtain personal health information about a deceased individual?

When a person dies, the estate trustee or the person who has assumed responsibility for the administration of the deceased's estate, if the estate does not have an estate trustee, becomes the substitute decision-maker for the deceased individual. In many cases, the estate trustee will be a member of the deceased's family.

The term "substitute decision-maker" generally refers to a person who is authorized under *PHIPA* to consent on behalf of an individual to the collection, use or disclosure of personal health information about the individual. The substitute decision maker is also authorized to make a request, give an instruction, or take a step on behalf of the deceased individual where *PHIPA* permits or requires such a step or other action.

Under *PHIPA*, every individual has the right to request access to records containing his or her own personal health information in the custody or control of a health information custodian. Where the individual is deceased, the substitute decision-maker may make such a request on behalf of the deceased individual. Where the health information custodian grants the access, the substitute decision-maker also has the right to request that the record be corrected.

There are some exceptions to the right to access a record of personal health information. Requests may be made using the form entitled, *Request to Access Personal Health Information (PHIPA)*, available at:

www.ipc.on.ca/images/Resources/up-hipa_accfrm_e.pdf



How does a health information custodian determine whether a person is the substitute decision-maker for the deceased individual?

As noted above, when an individual dies, the estate trustee or the person who has assumed responsibility for the administration of the deceased's estate becomes the substitute decision-maker for the deceased individual.

"Estate trustee" is not a defined term in *PHIPA*. It is, however, defined in Rules 74 and 75 of Regulation 194 under the *Courts of Justice Act* as "an executor, administrator or administrator with the will annexed."

The term "executor" generally means a person named by the deceased in his or her will to carry out the provisions in that will. The term "administrator" generally means a person appointed by the court to administer the deceased's estate where there is no will. The term "administrator with the will annexed" generally means an administrator appointed by the court to carry out the provisions of a will when the will names no executor or the executor named refuses, is incompetent to act or has died.¹

The "person who has assumed responsibility for the administration of the deceased's estate" is also not a defined term in *PHIPA*, but it may include, for example, a person who has been appointed by the court to represent the interests of the deceased's estate where there is no estate trustee, or a person who is not so appointed but who, for valid reasons, has assumed responsibility for managing the affairs of the deceased's estate.

To date, the IPC has not issued any orders under *PHIPA* that interpret the terms "estate trustee" or "person who has assumed responsibility for the administration of the deceased's estate."

Under *PHIPA*, a health information custodian is entitled to rely on the accuracy of a person's assertion that he or she is the substitute decision-maker for the deceased individual, unless it is not reasonable to do so in the circumstances.

In circumstances where it is not reasonable to rely on a person's assertion that he or she is the authorized substitute decision-maker for the deceased individual, the health information custodian may decide to ask the person asserting that he or she is the substitute decision-maker to provide documentation verifying his or her authority as such or attesting to such authority, and request identification to be satisfied as to the individual's identity.

What obligations are imposed on the substitute decision-maker for the deceased individual?

A substitute decision-maker is required to take certain factors into consideration when acting on behalf of another individual regarding a collection, use or disclosure of personal health information by a health information custodian.

In the case of a deceased individual, the substitute decision-maker must consider the wishes, values and beliefs that the substitute decision-maker knows the individual held when alive, and believes the individual would have wanted reflected in decisions made concerning his or her personal health information. Further, the substitute decision-maker must consider whether:

¹ See definitions of "executor," "administrator" and "administrator cum testamento annexo" in *Black's Law Dictionary*, 8th ed.



- the benefits from the collection, use or disclosure of the information outweigh the risk of negative consequences occurring as a result of the collection, use or disclosure, as the case may be;
- the purpose for which the collection, use or disclosure is sought can be accomplished without the collection, use or disclosure; and
- the collection, use or disclosure is necessary to satisfy a legal obligation.

Can a relative, who is not the substitute decision-maker, obtain the personal health information of a deceased individual?

Under *PHIPA*, A health information custodian may only disclose personal health information to a person who is not a custodian (such as a relative of a deceased individual), if:

- the individual whose personal health information is at issue has given express consent;
- the disclosure is permitted or required by *PHIPA*; or
- the disclosure is permitted or required by another law.

In the case of a deceased individual, the consent may be given by the deceased individual's substitute decision-maker.

This means that personal health information about a deceased individual may be disclosed by a health information custodian to a relative of the deceased individual, if the substitute decision-maker consents to the disclosure.

In addition, *PHIPA* permits a health information custodian to disclose personal health information about a deceased individual without consent in the following circumstances:

- for the purpose of identifying the individual;
- for the purpose of informing any person whom it is reasonable to inform in the circumstances of,
 - the fact that the individual is deceased or reasonably suspected to be deceased, and
 - the circumstances of death, where appropriate; or
- to the spouse, partner, sibling or child of the individual if the recipients of the information reasonably require the information to make decisions about their own health care or their children's health care.

PHIPA also permits the disclosure of personal health information by a health information custodian without consent in a number of other circumstances (e.g., to eliminate or reduce a significant risk of serious bodily harm). All of the permitted disclosures are set out in sections 38 through 48 and section 50 of *PHIPA*. While some of these provisions may be applicable in disclosing personal health information to relatives of deceased individuals, it is important to note that these disclosures are discretionary not mandatory.

In general, persons who are not custodians and who obtain personal health information about a deceased individual from a health information custodian may only use or disclose the information for the purpose for which it was disclosed or for the purpose of carrying out a statutory or legal duty.



If a health information custodian refuses to disclose personal health information to a relative of the deceased individual or refuses to provide access to the substitute decision-maker, is there any recourse?

If a health information custodian refuses to grant access to a substitute decision-maker or refuses to disclose personal health information about a deceased individual to a relative, a complaint may be made to the IPC. Complaints may be made using the form entitled, *Access/Correction Complaint Form*, available at:

http://www.ipc.on.ca/images/Resources/up-1phipa_accorrcmp_e.pdf

What if a deceased relative's personal information, including medical information, is not in the custody or control of a health information custodian?

If the personal information about a deceased individual is held by a provincial or municipal government institution that is not a health information custodian, such as a provincial government ministry, the Ontario Provincial Police, or a local police services board, then this information would be subject to Ontario's two public sector access and privacy laws: the provincial *Freedom of Information and Protection of Privacy Act (FIPPA)*, and the *Municipal Freedom of Information and Protection of Privacy Act (MFIPPA)*.

In these two *Acts*, "personal information" is defined to mean recorded information about an identifiable individual, including information relating to the medical, psychiatric, or psychological history of the individual. The complete definition of "personal information"

is found in section 2 of these *Acts*. Personal information does not include information about an individual who has been deceased for more than thirty years.

Under *FIPPA* and *MFIPPA*, a deceased individual's personal representative can exercise any right or power conferred on the deceased individual by the *Act*, including making a request for information, if doing so relates to the administration of the individual's estate.

In addition, *FIPPA* and *MFIPPA* contain provisions that may permit the disclosure of personal information about a deceased relative in certain circumstances. Section 42(1) of *FIPPA* and section 32 of *MFIPPA* set out the circumstances in which an institution may disclose personal information. These provisions are discretionary, not mandatory. For example, an institution may disclose personal information in compassionate circumstances, to facilitate contact with the spouse, a close relative or a friend of a deceased individual. Whether a particular disclosure of personal information fits within any of the provisions in section 42(1) of *FIPPA* or section 32 of *MFIPPA* will depend on the specific circumstances.

FIPPA and *MFIPPA* also provide that in the case of a request by the spouse or a close relative of a deceased individual for personal information about the deceased individual, disclosure of the personal information to those individuals does not constitute an unjustified invasion of privacy if the head of the institution is satisfied that, in the circumstances, the disclosure is desirable for compassionate reasons.

A spouse or close relative requesting information about a deceased individual is required to give the head of the institution all information that he or she has regarding whether the deceased



individual has a personal representative and how to contact him or her.

Requests for information under FIPPA or MFIPPA may be made using the *Request Form*, available at: www.ipc.on.ca/images/Resources/up-form_2e.pdf

If a government institution refuses to provide a deceased individual's personal information to a relative or to the personal representative in response to an access request, is there any recourse?

If a government institution refuses to provide a relative or personal representative with the personal information of a deceased individual in response to an access request, the institution's decision may be appealed to the IPC using the *Appeal Form* available at:

http://www.ipc.on.ca/images/Resources/up-appfrm_e.pdf

How are the results of a coroner's investigation obtained and who is entitled to the information?

For information about whether and how a person may obtain the results of a coroner's investigation, including pathologist's and toxicologist's reports, contact the Regional Supervising Coroner's Office, or the Office of the Chief Coroner, part of Ontario's Ministry of Community Safety and Correctional Services. Their office is located at

26 Grenville Street, 2nd floor, Toronto, Ontario M7A 2G9, and the phone number is (416) 314-4000. For more information you can visit their website at:

http://www.mcscs.jus.gov.on.ca/english/office_coroner/about_coroner/coroner_what/coroner_what.html

How can a death certificate and other related information concerning a deceased relative be obtained?

Applications for death certificates for deceased individuals may be made online. The Office of the Registrar General's Online Certificate Application form is available through ServiceOntario at:

<https://www.orgforms.gov.on.ca/eForms/start.do?lang=en>

In some circumstances, an application may be made for additional information, such as a medical certificate of death. For more information, contact the Office of the Registrar General, part of Ontario's Ministry of Government Services, at:

Office of the Registrar General
P.O. Box 4600
189 Red River Road, 3rd Floor
Thunder Bay ON P7B 6L8

In Toronto 416-325-8305
Toll-free Outside Toronto 1-800-461-2156
Fax: (807) 343-7459

Fact Sheet

is published by the **Office of the Information and Privacy Commissioner of Ontario**.

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Website: www.ipc.on.ca
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